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Award Number:

W81XWH-09-1-0022

TITLE:

The PAN 15th Annual Research & Education Forum

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CONTRACTING ORGANIZATION:

Parkinson's Action Network (PAN)
Washington, DC 20005

REPORT DATE:

April 2009

TYPE OF REPORT:

Final

PREPARED FOR: U.S. Army Medical Research and Materiel
Command

Fort Detrick, Maryland 21702-5012

DISTRIBUTION STATEMENT:

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REPORT DOCUMENTATION PAGE				Form Approved OMB No. 0704-0188	
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1. REPORT DATE (DD-MM-YYYY) 01-04-2009		2. REPORT TYPE Final		3. DATES COVERED (From - To) 3/15/09 to 3/17/09	
4. TITLE AND SUBTITLE The PAN 15 th Annual Forum				5a. CONTRACT NUMBER	
				5b. GRANT NUMBER W81XWH-09E1E0022	
				5c. PROGRAM ELEMENT NUMBER	
6. AUTHOR(S) Amy Comstock Rick, JD, Principal Investigator				5d. PROJECT NUMBER	
				5e. TASK NUMBER	
				5f. WORK UNIT NUMBER	
7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES) Parkinson's Action Network (PAN) 1025 Vermont Ave., NW #1120 Washington, DC 20005				8. PERFORMING ORGANIZATION REPORT NUMBER	
9. SPONSORING / MONITORING AGENCY NAME(S) AND ADDRESS(ES)				10. SPONSOR/MONITOR'S ACRONYM	
				11. SPONSOR/MONITOR'S REPORT NUMBER(S)	
12. DISTRIBUTION / AVAILABILITY STATEMENT Approved for public release; distribution unlimited					
13. SUPPLEMENTARY NOTES N/A					
14. ABSTRACT This conference grant supported the Parkinson's Action Network (PAN)'s 15th th Annual Research and Education Forum for Parkinson's patients, their families/caretakers and advocates held March 15 to 17, 2009 at the L'Enfant Plaza Hotel, Washington, DC. This forum brought together some of the foremost doctors and scientists working on Parkinson's research to share their work with patients and leaders in the Parkinson's community. PAN's Research and Education Forum serves as a premier educational program for Parkinson's physicians, patients, researchers as well as leaders in the Parkinson's community. The primary goal of the Forum is to bring together these various stakeholders so that they can share information and learn about the latest developments in Parkinson's research. Through plenary sessions, workshops and networking opportunities, participants will learn about the latest research and discuss creative ideas for new research endeavors. Fundamental to the success of the Forum is the premise that visiting scientists and researchers can learn from each other and from Parkinson's patients and caregivers.					
15. SUBJECT TERMS Panels included: National Parkinson's Organizations Panel; Department of Defense Neurotoxin Exposure Treatment Parkinson's Research Program Panel; Understanding the Scientific "Valley of Death" Panel; and an Emerging Therapies in Parkinson's Panel.					
16. SECURITY CLASSIFICATION OF:			17. LIMITATION OF ABSTRACT	18. NUMBER OF PAGES	19a. NAME OF RESPONSIBLE PERSON USAMRMC
a. REPORT U	b. ABSTRACT U	c. THIS PAGE U			19b. TELEPHONE NUMBER (include code) 2

Table of Contents

Introduction.....	5
Body.....	5-6
Key Research Accomplishments.....	N/A
Reportable Outcomes.....	N/A
Conclusions.....	7
References.....	N/A
Appendices.....	8

Introduction

The Parkinson's Action Network (PAN) held its *15th Annual Research and Education Forum* for Parkinson's patients, their families/caretakers and advocates from March 15 to 17, 2009 at the L'Enfant Plaza Hotel, Washington, DC. The Forum brought together some of the foremost doctors and scientists working on Parkinson's research to share their work with patients and leaders in the Parkinson's community. 300 Parkinson's patients and families/caretakers attended "live". An additional 300 people participated via the live web cast. We anticipate that hundreds more will access all or part of the web cast over the coming months. The web cast is available on PAN's website all year at <http://www.parkinsonsaction.org/2008-Forum-Webcast.html>. Each year, this feature receives more than 2,000 "hits". We expect that number to grow this year as our outreach continues to grow.

Of the 300 participants, eight (8) were physicians, five (5) were researchers, ten (10) were leaders of other Parkinson's disease organizations throughout the country, ten (10) were corporate sponsors from pharmaceutical companies serving the Parkinson's community, and two hundred and sixty-seven (267) were Parkinson's patients and/or caregivers. Approximately 25% of the participants in the 2009 Forum were first time participants..

The U.S. Army's Medical Research and Material Command's grant of \$45,000 helped to support this important research and education program.

PAN's Research and Education Forum serves as a premier educational program for Parkinson's physicians, patients, researchers as well as leaders in the Parkinson's community. The primary goal of the Forum is to bring together these various stakeholders so that they can share information and learn about the latest developments in Parkinson's research. Through plenary sessions, workshops and networking opportunities, participants will learn about the latest research and discuss creative ideas for new research endeavors. Fundamental to the success of the Forum is the premise that visiting scientists and researchers can learn from each other and from Parkinson's patients and caregivers.

Body

This year's forum provided several informative panels including: National Parkinson's Organizations Panel; Department of Defense Neurotoxin Exposure Treatment Parkinson's Research Program Panel; Understanding the Scientific "Valley of Death" Panel; and an Emerging Therapies in Parkinson's Panel..

Program sessions included:

SUNDAY, MARCH 15, 2009

7:30 – 8:30 am	Registration Check-in/Breakfast
8:30 – 8:50 am <i>Ballroom</i>	Welcome & Introduction Amy Comstock Rick, Chief Executive Officer, Parkinson's Action Network
8:50 – 9:00 am	Break
9:00 – 10:30 am <i>Ballroom ABC</i>	Breakout 1: Introductory Advocacy Training Hayley Carpenter, Director of Outreach, Parkinson's Action Network
<i>Ballroom D</i>	Breakout 2: Advanced Advocacy Training Mary McGuire Richards, Deputy Chief Executive Officer, Parkinson's Action Network
<i>Location TBD</i>	Breakout 3: Scientific Professionals Advocacy Training Amy Comstock Rick, Chief Executive Officer, Parkinson's Action Network
10:30 – 10:45 am	Break
10:45 – 11:30 pm <i>Ballroom</i>	Plenary Session: Department of Defense Neurotoxin Exposure Treatment Parkinson's Research Program Colonel Karl Friedl, Ph.D., Director, Telemedicine and Advanced Technology Research Center, U.S. Army Medical Research and Materiel Command; Robert L. Kane, Ph.D. ABPP-Cn, Director, Neurocognitive Assessment Tool (NCAT) Program DVBIC
12:00 – 12:15 pm <i>Solarium</i>	Break/Pick-up Box Lunch
12:15 – 1:15 pm <i>Ballroom</i>	Box Lunch Keynote Speaker: Kevin Eggan, Ph.D., Assistant Professor, Department of Stem Cell and Regenerative Biology, Harvard University Introduction: Story C. Landis, Ph.D., Director, National Institute of Neurological Disorders and Stroke
1:15 – 1:30 pm	Break
1:30 – 2:30 pm	Plenary Session: Valley of Death

Ballroom	<i>Peter T. Lansbury, Jr., Ph.D., Professor of Neurology, Center for Neurologic Diseases, Brigham and Women's Hospital, Harvard Medical School;</i> Greg Simon, President, FasterCures
3:00 – 3:15 pm <i>Solarium</i>	Break with Refreshments
3:15 – 5:00 pm <i>Ballroom</i>	Plenary Session: Emerging Therapies Panel Moderator: Howard J. Federoff, MD, PhD, Executive Vice President and Executive Dean, Georgetown University Medical Center Panel: Krai Chatamra, PhD., Senior Clinical Research Director & Global Clinical Director, Solvay Pharmaceuticals Medtronic Neuromodulation (rechargeable battery for DBS); <i>Other Panelists TBD</i>
6:00 – 7:00 pm <i>Solarium</i>	Cocktail Reception
7:00 – 8:30 pm <i>Ballroom</i>	Samuelson Awards Dinner

Monday, March 16, 2009

8:00 – 9:00 am <i>Ballroom</i>	Registration Check-in/Breakfast Seating by Teams
9:00 – 10:30 am <i>Ballroom</i>	Plenary Session: National Parkinson's Disease Registry Moderator: Shawn O'Neil, Vice President - Federal Government Relations, National Multiple Sclerosis Society; Panel: Caroline M. Tanner, M.D., Ph.D., Director of Clinical Research, The Parkinson's Institute; Nicholas LaRocca, Ph.D., Vice President, Health Care Delivery and Policy Research, National Multiple Sclerosis Society.
10:30 – 10:45 am	Break
11:15 – 12:15 pm <i>Ballroom</i>	Plenary Session: RCDC Timothy Hays, Ph.D., Project Director, Research, Condition, and Disease Categorization Project, National Institutes of Health
12:15 – 12:30 pm <i>Solarium</i>	Break/Pick-up Box Lunch
12:30 – 1:30 pm <i>Ballroom</i>	Hill Day Logistics/Team Lunch Jennifer Sheridan, Program Manager, Parkinson's Action Network

1:30 – 3:15 pm

Parkinson's Disease Organizations Town Hall Meeting

Ballroom

Moderator: Jackie Hunt Christensen, Public Affairs Senior Advisor and Minnesota State Coordinator, Parkinson's Action Network

Panel: Robin Elliott, Executive Director, Parkinson's Disease Foundation;
Joel Gerstel, Executive Director, American Parkinson's Disease Association;
Katie Hood, Chief Executive Officer, Michael J. Fox Foundation;
Joyce A. Oberdorf, President and CEO, National Parkinson Foundation;
Amy Comstock Rick, Chief Executive Officer, Parkinson's Action Network;
Carol Walton, Chief Executive Officer, Parkinson Alliance/Unity Walk.

3:15 – 3:30 pm

Break with Refreshments

Solarium

3:30 – 4:00 pm

Keynote Speaker: Representative Chris Van Hollen

Ballroom

Introduction: Amy Comstock Rick, Chief Executive Officer, Parkinson's Action Network

4:00 – 5:15 pm

Advocate-Led Breakout Sessions

Ballroom D

1 Are You a Brainiac?

Peggy Willocks, Kentucky State Coordinator, Parkinson's Action Network;
Ken Cater, Alabama Congressional Coordinator, Parkinson's Action Network.

Montcalm

2 Asian Healing Arts

Rachel Gimbel, Shiatsu Massage Practitioner;
Debra Pressman-Gimbel, Virginia Congressional Coordinator, Parkinson's Action Network

Ballroom ABC

3 DBS 101.5

Michael Church, Florida State Coordinator, Parkinson's Action Network;
Gretchen Garie-Church, Florida Congressional Coordinator, Parkinson's Action Network;
Carol Meenen, Senior Advisor for the Newly Diagnosed and Alabama State Coordinator, Parkinson's Action Network

Marquette

4 Rock Steady Boxing

Paula Tomlin, Indiana Co-State Coordinator, Parkinson's Action Network;

Scott Newman, President and Founder, Rock Steady Boxing Foundation;
Vince Perez, Vice-President and Co-founder, Rock Steady Boxing Foundation;
Kristy Follmar, Executive Director, Rock Steady Boxing Foundation.

5:00 – 5:45 pm
Solarium

Refreshments

5:00 – 5:30 pm
Ballroom Foyer

PAN Staff Available at Registration Table for Hill Day Questions

This project was directly relevant to the Department of Defense’s Neurotoxin Exposure Treatment Research Program (NETRP) since Parkinson’s Disease is a central focus of this program because of the importance of environmental factors, such as exposures to specific toxins, in the disease.

Conclusions

PAN’s *15th Annual Research and Education Forum* provided hundreds of Parkinson’s patients and their families/caretakers with important information about Parkinson’s disease research. Parkinson’s physicians, patients, researchers as well as leaders in the Parkinson’s community came together for a 3-day program packed with plenary sessions, workshops and networking opportunities.

Appendices

PAN Board of Directors

Anne Udall, Ph.D., Chair/Founding Chair -- North Carolina

Dr. Anne Udall is the Executive Director of The Lee Institute. She is the daughter of the late Representative Morris K. Udall. She also serves as Vice Chair of the Udall Foundation. Dr. Udall has more than 20 years experience as an educator, facilitator, and trainer. She served as the Assistant Superintendent of Curriculum and Instruction for Charlotte-Mecklenburg Schools in North Carolina.

John Rogers, Vice Chair-- Wisconsin

John Rogers is the President of Government Affairs for Whyte Hirschboeck Dudek Government Affairs, LLC, a leading public affairs firm. He is a national leader in the stem cell political and strategic arenas and a consultant to high-tech and biotech companies, research organizations, patient groups, and individuals. Mr. Rogers is a founding Executive Board Member of the Coalition for the Advancement of Medical Research (CAMR). He has been working on behalf of PAN since July 2000.

Mary Helen "Monnie" Lindsay, J.D., Treasurer -- Nebraska

Monnie Lindsay has been PAN's Nebraska state coordinator since 2005. She currently serves on the board of the local chapter of the American Parkinson's Disease Association (APDA). Ms. Lindsay also is a member of the Parkinson's Disease Working Group of the Collaborative on Health and the Environment. She co-authored the Parkinson's community's suggested new definition of Parkinson's disease for the Department of Health and Human Services. She is an attorney. Ms. Lindsay joined the PAN Board in 2006.

Jodie T. Allen -- Washington, D.C.

Jodie Allen serves as Senior Editor at The Pew Research Center, a nonpartisan "fact tank" that provides information on the issues, attitudes and trends shaping America and the world. Prior to joining The Pew Research Center, Mrs. Allen worked for U.S. News & World Report, where she was a managing editor and the author of a column on the political economy. Mrs. Allen also served as Washington bureau chief for Slate magazine, editor of The Washington Post "Outlook" section and a member of the Post's editorial page staff. In addition, Mrs. Allen spent part of her career as a policy analyst, focusing on demographic and political trends affecting tax and transfer payment programs. Mrs. Allen joined the PAN board in December 2008.

Frank Carlucci -- Washington, D.C.

Frank Carlucci has been a Managing Director of the Carlyle Group since 1989, Chairman since 1993 and Chairman Emeritus since January 2003. Mr. Carlucci was Secretary of Defense from November 1987 through January 1989, following his service as Assistant to the President for National Security Affairs under President Reagan. Before serving in these positions, Mr. Carlucci was Chairman and CEO of Sears World Trade, a business he joined in 1983. Mr. Carlucci preceded his affiliation with Sears World Trade with a career in government service, which included Deputy Secretary of Defense (1980-82), Deputy Director of Central Intelligence (1978-80), U.S. Ambassador to Portugal (1975-78), Under Secretary of Health Education and Welfare (1973-75), Deputy Director of OMB (1970-72), and Director of the Office of Economic Opportunity (1969). Mr. Carlucci was a Foreign Service Officer from 1956 to 1980 and he served as an officer in the U.S. Navy from 1952 to 1954. Mr. Carlucci began his service to the PAN Board in January 2005.

Robin Anthony Elliott -- New York

Mr. Elliott has been Executive Director of the Parkinson's Disease Foundation, Inc. (PDF) since October 1996. He has been active in development, communications, and not-for-profit management in New York City for more than 30 years. In that time, he has served as Vice President for Development and External Affairs at Teachers College, Columbia University (1988-95) and (with the same title) at Hunter College, City University of New York (1982-88); as Deputy to the Chancellor for University Relations at the City University of New York (1979-82); and as director of information and education at the Planned Parenthood Federation of America (1971-79). Mr. Elliott began his service to the PAN Board in March 1998.

Ronald H. Galowich, J.D. -- Illinois

Ronald H. Galowich co-founded Initiate Systems and has served as a member of the board of directors and

as its Chairman, since its inception in October 1994. He previously served as the Chief Executive Officer from October 1994 to July 2002. Mr. Galowich was a co-founder of First Health Group Corp., a publicly traded company, and held various positions, including serving as a director from June 1982 to February 2005, and as secretary, general counsel and executive vice president. He also served as the chairman of the audit committee and the compensation committee of First Health Group Corp. In addition to serving on the board of directors for Initiate Systems, Ron serves on the boards of directors of a number of private and not-for-profit corporations and was a director of real estate operations for the Pritzker Family from April 1981 to November 1990. He holds a B.S. and a J.D. from University of Illinois. Mr. Galowich joined the PAN Board in January 2008.

Katie Hood -- New York

Katie Hood was named Chief Executive Officer of The Michael J. Fox Foundation for Parkinson's Research (MJFF) in December 2007. She has played critical roles in shaping MJFF's strategy of intervening aggressively to close critical gaps that slow potential treatments on their path from the laboratory to Parkinson's patients, as well as in building a team of in-house research experts needed to implement that strategy. Prior to joining the Foundation in September 2002, Ms. Hood was employed as a consultant at Bain & Company in New York City, doing work in the consumer products, financial services, and nonprofit sectors. She has also served as an analyst in the Credit Department of Goldman, Sachs & Co., and as a program coordinator with Duke University's Hart Leadership Program. Ms. Hood graduated from Harvard Business School, and holds a B.A. in Public Policy Studies from Duke University. Ms. Hood joined PAN's Board of Directors in January 2008.

Morton Kondracke -- Washington, D.C.

Morton Kondracke is the Executive Editor of the Capitol Hill newspaper, Roll Call, a columnist, and commentator for Fox News. He is also the author of *Saving Milly: Love, Politics and Parkinson's Disease*; published in 2001. Mr. Kondracke serves on the Board of the Michael J. Fox Foundation for Parkinson's Research. His wife, Milly Kondracke, lost her long struggle with Parkinson's disease in July 2004. Mr. Kondracke began his service on the PAN Board in April 1996.

Barbara Kupperman -- Virginia

In addition to serving on PAN's Board, Barbara Kupperman is also on the Board of Directors for the Institute for Spirituality and Health at George Washington University Medical School. Mrs. Kupperman has been involved in political and non-profit fundraising for over 30 years, including her work with Sen. Robert Dole, The National Journal, The Center for Strategic and International Studies, the Republican National Convention, and the U.S. Committee for the Battle of Normandy Museum. Mrs. Kupperman is originally from Georgia, but now resides in Alexandria, Virginia. She was married to the late Robert H. Kupperman, who was diagnosed with Parkinson's disease 16 years ago and died in 2006. Mrs. Kupperman was elected to the PAN Board in July 2005.

Joyce A. Oberdorf -- Florida

Ms. Oberdorf was named President and Chief Executive Officer of the National Parkinson Foundation in March 2008. Prior to her position at NPF, Ms. Oberdorf was Vice President, Policy, Planning and Communications for the Michael J. Fox Foundation for Parkinson Research. In that role, she was responsible for strategic planning projects, public policy and communications and marketing. Prior to joining the Fox Foundation, Ms. Oberdorf was Vice President, Corporate Public Relations at Aetna Inc., one of the nation's leading health insurance providers. In addition to oversight of all corporate and financial communications, as part of the senior management team, she was also tapped to help devise strategies for broader projects, such as corporate center restructuring and revamping health business products to be more consumer-centric. Ms. Oberdorf holds an A.B. degree, cum laude, from Douglass College, Rutgers University and an M. A. degree from Northern Illinois University.

Cheryl Lynn Prescott -- Wisconsin

Cheryl Lynn Prescott has served as a PAN Congressional Coordinator for the 5th Congressional District of Wisconsin since 2004. Her father, George Prescott, the former owner and chief executive officer of Prescott Supermarkets, Inc., announced his diagnosis of Parkinson's disease in 2001. Ms. Prescott is also on the Board of Directors of the Wisconsin Parkinson's Association, an organization of over 7,000 members and 60 support groups. She was elected to the PAN Board in October 2005.

Ian Rolland -- Indiana

Ian M. Rolland is the retired Chairman of Lincoln National Corporation. He joined Lincoln National Life in 1956 and has held numerous positions within the company prior to being named chairman, chief executive officer and president in 1997. Mr. Rolland earned a B.A. from DePauw University and a Master's degree in

Mathematics from the University of Michigan. He serves on the Boards of NIPSCO Industries, Inc., Bright Horizons Family Solutions and Tokheim Corporation, Hudson Institute, Indiana Historical Society, University of Saint Francis, Indiana Fiscal Policy Institute, Indiana Chapter of the Nature Conservancy and a member of the advisory board of CID Ventures and CID Partners. Additionally, he serves on the Boards of local community organizations which include the United Way, Anthony Wayne Services, Convention and Visitors Bureau, Arts United of Greater Fort Wayne, Junior Achievement and the Courthouse Preservation Trust. Mr. Rolland joined the PAN Board in January 2008.

Carol Walton -- New Jersey

Carol Walton's dedication to advocacy started in 1981, when her father was diagnosed with Parkinson's disease. In 1994, Carol attended the PAN Forum and became an advocate for research. She spent a lot of time walking the halls of Congress - and helped to get the Morris K. Udall Parkinson's Research Act passed in 1997. During that forum, she met Margaret and Martin Tuchman who were also advocates and wanted to raise funds for research. They lived in New Jersey and offered Carol the opportunity to head their foundation. In 1999, Walton moved to New Jersey to start the Parkinson Alliance.